

LE Magazine December 1999

PROFILE

She's Back!

A woman reclaims her life after battling fibromyalgia

It was almost 10 years ago that Dana Shapiro, now 41, first noticed that something was wrong. It started with a feeling of light-headedness, then she noticed some dizziness and soon after felt that her memory was slipping. New symptoms emerged with alarming frequency. After about six years she was feeling tired nearly all the time and then the pain came—and it was everywhere from her head to her toes and especially bad in her hips. She remembers the pain as being so searing that it was often impossible to lift her leg over and into the tub to take a bath.

"The only way to describe it is that horrible feeling you have right before you come down with the flu," she says. "Only that feeling stays with you 24 hours a day, seven days a week."

Only slightly less devastating than her physical symptoms was the medical community's inability to figure out what was causing them. During a trip to Seattle one doctor dismissed her illness as a one-time panic attack. Back home in Florida, another physician tested Shapiro for allergies, and still another prescribed an anti-depressant before finally taking her aside to tell her that there was, in fact, nothing wrong with her. Countless MRIs, catscans, X-rays, and blood tests followed, until a day two years ago when Shapiro was sitting in the office of yet another new primary care physician. After she explained her symptoms, he recommended that she see a rheumatologist and be tested for fibromyalgia syndrome (FMS)—a dysfunction of the biochemical informational substances such as peptides, hormones and neurotransmitters. Among the common, wide-ranging symptoms of FMS are chronic fatigue, depression, insomnia and constant, widespread pain.

There are 18 specific tender points, or trigger points, on the body, which would likely be painful in the case of a positive diagnosis of FMS. Of the 12 trigger points that Shapiro was tested for, 11 proved to be extremely painful. (FMS is not detectable by a blood test or X-ray.) Though the disease is incurable—the best hope is that the symptoms eventually wane in intensity—Shapiro found great comfort in the news. "I had thought I was losing my mind," she remembers. "So, I feel better knowing that at least I'm not going crazy."

FMS affects every age group, striking women at a ratio to men of 20 to one. Between 7 and 10 million Americans suffer from it—many of them without knowing. Though FMS is thought to be caused by trauma (Shapiro once broke both her back and her neck) or stress, or to be inherited, not a great deal is known about the disease or how to treat it. Shapiro's best nugget of advice on how to manage her illness came from a doctor who told her to keep trying things until she hit on something that worked. With that motto in mind, Shapiro sought out healing experts from acupuncturists to nutritionists before settling on a routine of strenuous exercise, a healthy diet, and plenty of supplements and vitamins.





The first component in her treatment regime-exercise-came naturally. When Shapiro first became sick she had been doing such rigorous weight training that her percent of body fat had dropped to just 14. (An average women has 20 to 30 percent body fat, while a very fit woman might have a body fat percent in the low 20s.) Today, her path back to health includes twice weekly Tae Bo classes and twice weekly weight-training sessions. She also has a stairmaster at home, which she uses when she can't get to the gym, rollerblades, and never travels without her resistance bands. Her workouts last a minimum of an hour and a half and she tries to work out at least four days a week. "If I don't work out I start getting achy again after just a couple of days," she says. Still, as rigorous as her Tae Bo class is, Shapiro finds that FMS affects her breathing, leaving her winded as she walks up the three flights to her apartment.

Shapiro's dedication to good diet was a little harder to cultivate-she admits her eating habits were "bad" before she became sick. Today she tries to steer clear of all processed foods, opting instead for fresh fruits and vegetables, and chicken. She won't eat or drink anything with aspartame in it, such as diet sodas, because the artificial sweetener aggravates most FMS symptoms. She consumes five times

the amount of protein she used to by drinking plenty of protein shakes. "I'm fairly good with it, because I know it makes me feel better," she says about her dietary habits. "If there's one thing I've learned from this it's that you have to listen to your body. I never used to do that-I'd be thoroughly exhausted and I'd just make myself keep going."

Shapiro is a great believer in cetyl myristoleate, a treatment that is typically taken as a one-time cure and often recommended for people who struggle with FMS or arthritis. Shapiro, for example, took six capsules per day over a 30 to 40 day period last winter. "It didn't work that quickly," she remembers. "But I had a lot more symptoms than other people and it took me awhile to realize that I wasn't in as much pain." (She recently went back on it.) Shapiro also did a one time 30-day stint on NADH5, which can also be taken on a daily basis, to help stem memory loss and boost her energy level.

As part of her daily routine, Shapiro turns to twice daily doses of a mega multi vitamin, takes one gel cap of essential fatty acids and four tablets of spirulina twice daily to be sure she's getting her greens. Then there's calcium because "it can't hurt"-and malic acid/ magnesium two or three times a day, which is highly recommended for FMS symptoms. Because her metabolism pretty much shut down in recent years, Shapiro uses thyroid starters. (Studies show that FMS patients suffer from hypothyroidism at a rate much higher than the general population.) Recently she began taking MSM to help with the arthritis symptoms and she takes St. John's Wort daily to keep the blues at bay.

"I make little pill packs and I don't go anywhere without them," she says. The final element in Shapiro's health regime is rest. She continues to set aside one day a week to sleep, finding that rejuvenates her not only from her disease, but also from her normal 12-14 hour days away from the home. For the last two years she's served as a vice president for the Fort Lauderdale office of a mortgage company and is proud to note that "there hasn't been a day in a long time" when she's been too sick to go to work.

A hectic professional life is certainly a welcome change from the empty days of past years when Shapiro was far too ill to venture outside the home-unless it was to the doctor's office. "You kind of pull yourself out of society," she says. "You can't make plans because you never know what you're going to feel like, so you lose touch with people and your friends get tired of hearing you say how sick you are when you look fine."

Not only did Shapiro end up losing touch with most of her friends, but the constant medical tests and experiments with new treatments nearly broke her financially. As a result she hit rock bottom, both physically and emotionally, about two and a half years ago. "I was at a low point for about a year," she recalls. "But then I had to pull myself out of it. Your life has to change. You start from scratch again."

One thing that has helped Shapiro get past the trauma of the disease is the chance to help other FMS sufferers benefit from her experience. "If you're really sick and don't know what to do, you need someone to talk to who's been through the same thing," she says, adding that she doesn't mind if people call her with questions. She'd like to let them know that they too can reclaim their lives. "I'm not saying that I'm there yet, but I'm a lot better than I was," she says. "My life revolved around this disease for awhile-now, I actually have a life."

-Twig Mowatt

Dana Shapiro can be reached by e-mail dllsource1@aol.com. Support and information inquiries regarding her personal experience with fibromyalgia are welcome.

These statements have not been evaluated by the FDA. These products are not intended to diagnose, treat, cure or prevent any disease. The information provided on this site is for informational purposes only and is not intended as a substitute for advice from your physician or other health care professional or any information contained on or in any product label or packaging. You should not use the information on this site for diagnosis or treatment of any health problem or for prescription of any medication or other treatment. You should consult with a healthcare professional before starting any diet, exercise or supplementation program, before taking any medication, or if you have or suspect you might have a health problem. You should not stop taking any medication without first consulting your physician.